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# Disability and Reproductive Health of Women: Exploring Barriers and a Way Forward

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**ABSTRACT**

*Disability is highly stigmatized, and people with disability are perceived to be dependent, incapable, passive and in need of care. The disabled population is never a homogeneous category; it consists of people from different class, gender and age. Nevertheless, disability impacts everyone in a different way. Disabled persons face discrimination in every society, but women with disabilities get discriminated to a greater extent. The dual oppression of ableism and sexism undoubtedly puts a disabled woman in an extremely marginalized position. Gender and disability are social constructions, so the conceptions of disability are highly contextual and subjective. Gender in itself is a vulnerable category in the discourse of disability studies. The accessibility of disabled males to various services is more, even the chances of marriage and choosing a life partner is considerably high than their female counter parts. Women with disabilities remain largely unheard of, and are often invisible from the social map of society. They undergo a multitude of problems, and some of the important areas remain their reproductive health needs, reproductive rights and related experiences. The reproductive health needs of disabled women have not received much attention because of the pre conceived notions that they are not sexually active, don't have reproductive needs, and are not capable of bearing and rearing children. They face various issues and challenges in accessing services related to their reproductive health needs. The challenges can range from physical, attitudinal, communicational barriers, to lack of awareness from the health care professionals, or the barriers created by the society itself.*

*Less attention has been paid to the reproductive health concerns of disabled women. Therefore, this paper will bring an overview of disabled women's reproductive health and explore the related problems faced by them. It will try to ascertain the role played by State and non State agencies. A possible intervention and a way forward will be given so as to create an enabling environment for them.*

***Key Words: Disability, Reproductive Health, Gender.***

## I. INTRODUCTION

According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRDP) Persons with disabilities are those who have long term physical, mental, intellectual or sensory impairments which in, interaction with various barriers, may hinder their full and effective participation in society on an equal basis

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with others (WHO, 2006). The definition given by the WHO defines disability as an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Impairment and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course (Thomas, 2012). Disability cannot only be pronounced as a health problem but it may be regarded as complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. An impairment eventually results into a disability because of the type of environment a person lives in, and the interaction of a person with that environment. Disability is a multidimensional concept, relating to the body functions and structures of people the natural environment, the built environment, culture, the economic system, the political system, and psychological factors and confound to social expectations determines the varying degrees of able-bodiedness or disability (Garland Thomson 1997). The Preamble to the UNCRPD acknowledges that disability is "an evolving concept, but also stresses that "disability results from the interaction between persons with impairments and attitudinal, environmental barriers that hinder their full and effective participation in society on an equal basis with others". The impact of disability varies according to the socio-economic status, gender, social and geographical locations. The ways in which bodies interact with socially engineered environments, which includes, the activities they do, the life areas in which they participate, and the factors in their environment that affect these experiences (WHO, 2000)." As the disabled population form one of the marginalized sections of any society, hence they have to face discrimination everywhere. Disabled people have been isolated, and judged by their individual (dis)abilities by the non-disabled world (Morris 1992). They always have to struggle for access and equality. There are barriers and restrictions created by the society that marginalizes them from rest of the population. A restricting environment can be in the form of physical barriers, communication barriers or the attitudinal barriers. Disability has been conceptualized as a power relationship between people with impairments and non-disabled people that devalues and excludes disabled people from mainstream society by constructing different acts/people as deviant, which reflects the power differentials in any particular society (Abberly 1991 cited in Gleeson 1997). Disabled persons are often marginalized on the basis and type of their disability as it can be of different types; it may be physical, intellectual or loco motor. It may be congenital or acquired. The restricting environment that is prevalent everywhere does not allow them to use their potential and capacities to the full. They often lack access to services particularly those related to health care. For the disabled person, the lack of opportunity to participate or socialize in the same manner as the able-bodied person may likewise serve to influence their perception of themselves as sexual beings, and their knowledge of sexual intercourse, reproduction, and preventive health care practices essential to quality reproductive health (Robinault, 1978).

While disabled people are marginalized from the rest of the world, but women with disabilities are found on the peripheries. There are many stereotypes and prejudices attached with the notion of being a disabled woman. To be a disabled woman is considered to be unable to perform the task and role of a home maker, a wife, a mother

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and also unable to conform to the notion of beauty as far as her physical appearance is concerned. She also fits well into the stereotype of dependency, incapability and passivity. In an Indian context a disabled women has to face a triple handicap because of her disability, gender and birth in a developing nation. The word disabled when appears as a prefix adds agony, pain and misery to the life of a woman. It also means less chances of equality in terms of education, employment, living arrangements, personal relationships, and opportunity in terms of freedom. At any given time, the people with mobility needs suffer tremendous hindrances mainly due to structural, physcological and socio- cultural barriers (Halder, 2008,2009) and same is true for women who are disabled. They have to face problems in almost every sphere of life. One such important area of concern is of their Reproductive health and sexuality. Disability and sexuality have not been viewed as a combined field because disabled women often fare as asexual in our society. They emerge as sexually incapable section of society. The reproductive health needs of disabled women are seldom considered because of the pre-conceived notion that disabled women are asexual and are not capable of bearing and rearing children. They are not been viewed as capable mothers. As such their reproductive health has not been a concern for the stake holders.

## II.WHAT DOES REPRODUCTIVE HEALTH MEAN?

The RCH programme is the outcome of ICPD Conference which was formally launched by the Ministry of Health and Family Welfare, Government of India in October 1997. The major components of the programme include:

- Prevention and management of unwanted pregnancy,
- Services to promote safe motherhood including emergency obstetric care.
- Services to promote child survival including essential newborn care.
- Prevention and treatment of reproductive tract infections (RTIs) and sexually transmitted diseases (STDs).
- Establishment of an effective referral system.
- Reproductive services for adolescent health, sexuality, gender information, education and counseling.

In the ICPD program of action, 'Reproductive health' is defined as: “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed about, and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of birth control which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. In line with the above definition of reproductive health, reproductive health care is defined as the constellation of methods, techniques and services that contribute to reproductive health and well-being by preventing and solving reproductive health problems. It also includes sexual health, the

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purpose of which is the enhancement of life and personal relations, and not merely counseling and care related to reproduction and sexually transmitted diseases."

The ICPD recognized the centrality of sexual and reproductive health and rights to health and development. 'Sexual and reproductive health rights spans the life of both men and women, offering individuals and couples the right to have control over and decide freely and responsibly on matters related to their sexual and reproductive health, and to do so freely from violence and coercion'. Article 25 (a) of the 2006 Convention on the Rights of Persons with Disabilities (CRPD) articulates that persons with disabilities should have the same ranges quality, and standard of free or affordable health care and programs as provided to other persons. This includes sexual and reproductive health (SRH) services. Reproductive Health forms an important component of overall health of a person's life, particularly of a woman. In developing countries, majority of women lack an adequate access to reproductive health services which includes adequate care during pregnancy, providing of information and counseling on signs and symptoms of problems, referral as to where to seek the treatment if complications arise, and help women and their families prepare for child birth. Reproductive health conditions are estimated to account for between 5% and 15% of the overall disease burden, depending on the definition of reproductive health employed (Murray & Lopez, 1998). The WHO assessed in 2008 that "Reproductive and sexual ill-health accounts for 20% of the global burden of ill-health for women, and 14% for men." In India, considerable number of personnel and public health infrastructure was created consisting of various sub-centers, Primary Health Centers, dispensaries, urban family welfare facilities, and secondary and tertiary hospitals but still an effective management of RCH services is not done due to a number of constraints. The access and utilization of these services depend upon various factors such as socio-economic class, education level, age, level of awareness and resources available. While the access of women to these services may be generally low, but disabled women are particularly seen at the receiving end of health care system because of innumerous factors.

## III. BARRIERS

In India, disabled women constitute a considerable proportion of the total disabled population as the Census 2011 reveals that there are 26.8 million people in India with disabilities, out of which 15 million are men and 11.8 million are women, which mean females constitute 44.10 percent of the total disabled population. Disabled women face numerous challenges in accessing reproductive health care services and there is a lack of preparedness of the health care system to cater to their needs. These barriers can range from Socio-cultural, physical, attitudinal, communicational to lack of awareness.

1. **Policy Level Barriers:**

Different policies and laws are enacted for marginalized persons from time to time. These policies for the less privileged section of the society are in place to make them at par with the mainstream society. As disabled persons form one of the most marginalized sections of our society, thus government at central and state level have enacted several laws and policies which try to cater to their needs. These include Acts like Mental Health

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Act of 1987, the Rehabilitation Council of India Act of 1992, the People with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 (PWD Act), and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 1999 and the National Policy for Disabled 2006. The PWD Act of 1995 was the key central legislation that provides certain provisions in the areas of education, employment and other privileges in prevention and early detection of disabilities. It also stresses for accessible public modes of transportation such as railways and buses by requiring that these vehicles be modified in such ways as to make them accessible to people in wheelchairs, and calls for the installation of ramps in government buildings and public primary health centers. The National Policy for Persons with Disability (2006) is another important policy that provides a framework under which the state, civil society and private sector should operate to ensure a dignified life for persons with disability and support for their caretakers. The policy recognizes the need to replace the focus from medical rehabilitation to social rehabilitation. This policy also states that Community Based Rehabilitation (CBR) must be encouraged as it can be an effective means of rehabilitation.

Towards the end of reproductive health,several policies and programmes have been introduced time to time. These include the Janani Suraksha Yojana (JSY), ICDS Programme, and Reproductive Child Health Programme (RCH).

JSY 2005 is being implemented with the objective of reducing maternal and neo natal mortality by promoting institutional delivery among poor women. Besides this, India has also ratified the UN Convention on the Rights of Persons with Disabilities in 2007.UNCRDP is a basic instrument which stresses on the equality of disabled persons in all spheres of life. A specific mention has been given to the reproductive health in the Convention. Article 25 of the Convention stresses on the health issues and states “Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes”. The UNCRDP have also stressed upon the countries that have ratified the convention to provide polices and formulate them in tune with the recommendations and the Articles of the convention. Article 6 of the Convention specifically recognizes the obligation on States Parties to take measures to ensure that women and girls with disabilities are able to have full and equal enjoyment of all human rights and fundamental freedoms. As India has also ratified the Convention and accordingly it has to formulate policies in tune, so as to provide a better environment for disabled persons.

However, fact remains that disabled women in India are still subject to multiple disadvantages. This is because none of the policies talks specifically about the disabled women. In accordance with the UNCRDP, India has formulated certain policies but no clause has a specific mention for disabled women. These policies are for disabled people and not specifically for disabled women. So in a way clause for disabled women are by products of these policies rather than specifically addressing the issues concerning this poor lot. The JSY scheme has no special component for disabled women who are pregnant, and as such a policy level barrier is created for disabled women vis- a vis their reproductive health. Disabled women who are married need different care from

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their counter parts. A policy that is made for pregnant women in general cannot prove to be sufficient for disabled women as their needs are different. There is an inability of the State to remove barriers at policy level, which increases the problems manifold.

**2: Attitudinal Barriers:**

In any society women continue to be seen primarily in the reproductive roles – i.e., as child bearers and homemakers. The society decides that who is capable for these roles and in turn she gets acceptance in the social ambit by qualifying for these roles. This is the characteristic feature of a patriarchal society like India, in which women still face marginalization in general, and disabled women in particular. Women with disabilities continue to be the most marginalized section in Indian society who have to face various barriers in accessing services related to their reproductive health needs. The common notion that disabled women are asexual makes it difficult for them to access the related services. In a society obsessed with `perfection' and health, and intolerant of difference, non-disabled people view sexual activity by disabled people with discomfort or alarm (Waxman, 1993). Attitudinal barriers arise from negative societal beliefs about the worth of women with disabilities. These beliefs make it difficult for a disabled woman to get married and have children. Women with disabilities are likely to marry less often, marry later in life, have fewer children, and divorce more frequently than women without disabilities (Asch and Fine, 1997).They are also discouraged from having children as their disability is viewed as an impediment to their mothering. Many authors have argued that women undergo re socialization when they become mothers, in the process of transforming themselves into women who love, caring and responsible people, linking feminity and responsibility to female adulthood (McMohan, 1995) and such can be true for a disabled women. A common notion which hinders disabled women from becoming a mother is that that the child will inherit a disability and that a disabled woman cannot possibly be a good mother. Although a larger proportion of disabilities are not congenital, but develop later in life, the stigma of disability and the misconception that it is always hereditary result in attitudes that disabled women should not be permitted to bear children (Asch, 1988; Browne et al., 1985). It is often assumed that the disabled mother will hurt her child or be unable to provide for its needs (Shaul et al., 1985). People often assume that children seen with disabled women are likely adopted and even that they may be in danger (Saxton, 1984; Fine & Asch, 1988). A disabled woman is often viewed as a burden on family; as such her decision to become a mother is often rejected by the society.

**3. Barriers Created Due To Discriminatory Attitude of Health Professionals:**

Disabled women face difficulty when they visit health care services for reproductive and sexual health; they experience various difficulties, some of them being an inaccessible environment and insensitive providers. Disabled women struggle to find providers sensitive to their health concerns and to overcome physical barriers to medical facilities (Gill, 1993). These barriers may include disrespect from medical professionals and other staff, reluctance to communicate with women whose speech or hearing is impaired; lack of knowledge about

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particular disability and disabling conditions. The attitudes of these professionals regarding the disabled women as child bearers are largely based on myths rather than facts. Physicians often counsel disabled women not to have children merely because it has seemed obvious that people with disabilities would not make good parents (Kaplan, 1988). Disabled women with hearing and speech impairment find it difficult to communicate with the medical professionals regarding their health concerns and as such their needs are not met properly. These professionals are not trained well to handle sensitive patients. Physicians receive little training about or positive exposure to disabled people and virtually no education on the social context of disability, much less the interrelated impact of sexism, racism, or homophobia on women with disabilities' (Saxton, 1991). Disabled women have the same needs for reproductive and sexual health as other women. When disabled women present health problems, practitioners assume that these problems are related to their disability. They do not receive the same careful diagnoses and appropriate remedies as other patients. Providers can be misinformed or biased, prescribe inappropriate treatments, and ignore disabled women's knowledge of their bodies and needs (Simpson, 1992).Due to inaccessibility, lack of information, insensitive treatment and the assumption they are not sexually active, disabled women may not receive necessary reproductive and obstetrical care, or appropriate instruction on protecting themselves from sexually transmitted diseases (STDs) and AIDS (McCarthy, 1994). The many myths and misconceptions surrounding women with disabilities have resulted in the construction of negative prejudicial attitudes towards them, and hostility, sympathy and pity are common associated emotions (DeLoach, 1994). These emotions and prejudicial attitudes heighten women's sense of vulnerability, insecurity, isolation and marginalisation and increase the pressure experienced by women as they embark on, and attempt to negotiate, the many challenges of pregnancy (McGuinness, 2006).

4. **Physical Barriers:**

Disabled women face a number of physical barriers while accessing health care services. The challenges and barriers experienced by them while accessing reproductive health services can have a varying impact on their health. Physical barriers may include the unavailability of transportation, written information; such as intake forms and patient education materials, not available in alternative formats (i.e. Braille, tape, large print); high examining tables and lack of personal assistance to women who need it during clinic visits. Research indicates that a substantial proportion of health care facilities and physician's offices are inaccessible to women with a physical or sensory disability (Campion, 1997; Welner, 1997; Grabois et al, 1999; DeJong et al, 2002; Smeltzer et al, 2007). Other obstacles that render health care facilities, physician's offices and clinics inaccessible include the physical location of facilities, offices and clinics, non availability of designated parking bays and the topography of pavements and curbs (Thomas and Curtis, 1997). For some women the stress and physical energy generated from trying to gain access is so intense that some would 'delay appointment making' (Scheer et al, 2003) rather than try to negotiate access to an inaccessible environment (Goodman, 1994; Nosek et al, 1995). Such barriers create hindrances, which often have a negative impact on the health of a woman. Physical challenges which impede access convey the impression to women that they are unwanted, unwelcome and are a burden on health care providers (Kaplan, 2006). Disabled women can even find difficulty in completing their

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registration forms, finding an appropriate seat in the waiting area, and realising when to go into the examination room. Seeking a prior appointment and waiting for their turn can also create a hindrance as appointments are generally arranged around physician's and/or consultant's schedules and it can be difficult to obtain an appointment outside the scheduled hours (Clark, 2002). Waiting times for appointments are generally reported as too long (O'Doherty, 2006) and women's complex needs, which warrant assistance and extra time (Schopp et al., 2002). The availability of proper transport facilities also hamper the access to health care services and in some cases the distance of health care facilities from designated bus stops may be such that women may face additional barriers before reaching the health care facility. Driving independently may not be an option for some women with a physical (or sensory) impairment so they are reliant on public transport, taxis or other individuals when travelling to and from health care facilities (Anderson and Kitchin, 2000; Lawthers et al, 2003; Prilleltensky, 2003; Scheer et al, 2003). Depending on the woman's geographic location and the availability of suitable public transport, access to health care facilities may be hampered.

## IV.WAY FORWARD: A POSSIBLE INTERVENTION

Disabled women have an inherent right to be sexual beings, and have an equal access to reproductive health services as others have. A lot of disabled women lack the support to gain an equitable access to these services, which can arise due to various challenges. The environmental challenges that exist for people with disabilities are solvable (Moore, 1997) and all health care facilities should be made physically and socially accessible.Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental, attitudinal, social and physical barriers. These barriers can be broken down in a number of key ways which may include:

- A policy, Act or a programme enacted for disabled persons can have a varying impact on their lives. It is because an intervention at government level brings about large scale changes. The Government of India has enacted different policies and programmes for disabled persons, but all of them are not gender friendly. JSY and RCH programme caters to the reproductive health needs of women, but disabled women should have a separate policy or separate provision. The need is that the state should make specific policies for disabled women and these policies should take a holistic view of their problems and issues.
- All the Health care systems at primary and tertiary level must be strengthened and made self sufficient to cater to their needs. A specific budget allocation should be earmarked for the disabled women who need reproductive health assistance under the JSY scheme.
- An inter sector coordination between different departments will prove beneficial. As in Cameroon, for example, the involvement of the Ministry of Finance in the development of the reproductive health commodity security strategic plan helped raise awareness of the need to make provision for contraceptives in the national budget.

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- Inclusion of women and girls with disabilities in all programmes and policies should be done as the concept of inclusion assures that a policy is made from the need based approach. The concept of *"working for Disabled"* should change with *"working with Disabled"*. As quoted as an example of best practices in the United Nations Document Department of Economics and Social Policy, In 2008 the Italian Ministry of Foreign Affairs, General Directorate for Development Cooperation (DGCS), Central Technical Unit had started "Participatory process in the formulation of a National Disability Action Plan" in Kosovo. With the result the policies and legislations formulated were in accordance to the needs of the disabled people.
- There is a dire need to change the attitude of society, a change in the outlook of people where in they perceive disabled women as unworthy, asexual and incapable mothers. It is because of these prejudices and stereotypes that an inaccessible environment is created. As a result of which disabled women view themselves as inferior and don't find themselves a part of society.
- Awareness at a mass level should be done to address negative stereotypical views about the capability of disabled women as being mothers.
- An integration of disability studies must be done by integrating it with the curricula at the school, college, and the university level. The content must point towards their worth and dignity as human beings.
- Marriages of disabled women should be encouraged. Disabled women have less chance to get married because physical disability is being viewed as an impediment to their capacity of being a mother because of a general lack of understanding about disability.
- Doctors, nurses, and other clinic and hospital staff people should be trained to deal with patients with special needs. In addition, women with disabilities should be fully informed about their rights as patients.
- Special days and special appointments must be arranged for disabled women, so that they may not have to wait for long time.
- Medical Social Workers must be appointed at all the levels of health care systems, so that disabled women may get the necessary guidance and counseling where ever needed.
- Mobile clinics must be started to specifically cater to their needs and must be accompanied by a professional. Such clinics can keep a fixed day of visit, in order to reach to the unreachable.
- Physical access, accessible environment and access to information must be provided. Information must be provided in alternative language. Where ever feasible pictorial signage, Braille, audible, visual and tactile systems must be provided.

## V.CONCLUSION

Disability is a development issue and needs to be looked beyond the concept of impairment. Disability cannot be viewed as a problem concerning an individual only. It is a development issue and needs to be addressed. Although persons with disabilities experience marginalization but disabled women have to suffer more. A

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patriarchal set up that is prevalent in India paves way for gender inequality, gender bias which eventually permeates in all spheres of life. Disabled women have to face multitude of problems, with the main concern being them been viewed as asexual. It should be recognized how viewing disabled women as asexual functions as an impediment to their reproductive health issues. They share the same health, reproductive, and sexual needs and concerns as other women but they face a number of challenges in accessing the relevant services. All these host of social, political and cultural barriers create restricting environments for them. Although several policies have been enacted, yet a lot needs to be done for this marginalized section of the society. India has ratified the UNCRDP in 2007 and thus policy makers are obligated to frame policies in tune with the articles of the Convention. Implementing Article 6 of the UNCRDP is necessary which says that "women and girls with disabilities are subject to multiple discriminations and how State parties shall take appropriate steps to ensure their full development and advancement". Reproductive health forms an integral part of a woman's health but for disabled women it is an area of greater concern. The handicap they face due to the existing barriers need to be addressed with immediate effect. It must be remembered that this class forms an important and inalienable part of our society. Until and unless their issues are resolved and they aren't given their due in the society, we can never ever expect equitable development of our society.

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